Understanding Palliative Care in IPF

The term “palliative (PAL-ee-uh-tiv) care” is generally used to describe the effective management of common symptoms associated with a serious illness. The goal of palliative care is to improve or maintain a person’s quality of life throughout the disease experience. Palliative care comes from a coordinated, comprehensive approach to effectively manage your disease and its symptoms by all members of the healthcare team.
For people living with idiopathic pulmonary fibrosis (IPF), palliative care is considered a key component in the effective management of common symptoms. Palliative care should not be confused with end-of-life or hospice care. Instead, palliative care is used together with disease management and focuses on the whole person—the physical, emotional, spiritual, and social aspects that are individually important to you. Palliative care can begin at any time during your disease. Because it may help with many of your symptoms, it’s best to begin palliative care as early as possible.

EACH MEMBER OF YOUR HEALTHCARE TEAM WORKS TOGETHER TO SUPPORT YOUR EMOTIONAL, PHYSICAL, AND SOCIAL NEEDS THROUGHOUT THE MANAGEMENT OF YOUR CARE.

Palliative Care Focuses on the Whole Person

Palliative care addresses the physical aspects of IPF. Physical aspects include management of the disease and its symptoms, such as shortness of breath, fatigue, weakness, cough, and insomnia. Palliative care is key when identifying and managing side effects associated with therapy and/or specific medications. Palliative care provides support to the emotional aspects of living with IPF. Emotional aspects can include stress, anxiety, worry, and depression. Prompt recognition and early intervention are key in maintaining a sense of well-being. Palliative care ensures and promotes your individualized spiritual and
religious beliefs in care planning. Your healthcare team recognizes the importance and value this has on determining specific treatment decisions that are important and meaningful to you.

Palliative care recognizes the value of socialization. Effective disease and symptom management promotes physical functioning, which may allow you to engage in social activities that are important and meaningful to you. Socialization can be life-affirming and important in maintaining relationships and associations.

The healthcare team works together to provide palliative care in the routine medical management of IPF.

PALLIATIVE CARE PLACES YOU AT THE CENTER—YOU ARE IN CHARGE OF YOUR HEALTHCARE.

Together with the healthcare team, the goal of palliative care is to effectively manage the disease and its symptoms so that you may be able to do what is important and meaningful to you throughout the disease experience. It is important to discuss and establish a palliative care plan with your healthcare provider. This will allow you to remain actively involved in your care and maintain control. Research has shown that patients who utilize palliative care experience improved quality of life.
Beginning Palliative Care Early
Palliative care, or symptom management, works best when addressed soon after diagnosis with IPF. Research data suggests patients who began palliative care earlier in the courses of their disease had better quality of life than those who waited. This included improvements in symptoms such as anxiety, depression, and shortness of breath.

As IPF progresses over time, so do the symptoms. Your medical provider may adjust palliative care interventions to ensure symptoms are well managed. Palliative care interventions may intensify as the disease progresses and are often combined with hospice and end-of-life care.

Getting Started with Palliative Care for Your IPF
Your healthcare team is a good source of information about palliative care options. Taking control and being actively involved in your healthcare is important. Having meaningful discussions with your medical provider is key when determining their role in your symptom management. You may require a referral to a palliative care team within your community. Many medical centers offer a specialized palliative care team that includes doctors, nurses, social workers, pharmacists, chaplains, and other professionals.

MAKE SURE TO CHECK WITH YOUR INSURANCE CARRIER TO BETTER UNDERSTAND COVERAGE FOR PALLIATIVE CARE.

While disease and symptom management costs are routinely covered by insurance carriers, other types of supportive treatment, such as counseling or behavioral health, may not be reimbursable. In addition, you may have spending limits or high deductibles, depending on your unique plan. Remember, palliative care should not be confused with hospice care or end-
of-life care. Instead, it is a key component of your care to effectively manage common IPF symptoms and improve overall quality of life. Palliative care is an additional layer of support to your IPF care.